

Decision Making Following a Prenatal Diagnosis of Down Syndrome: An Integrative Review

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Introduction: Prenatal screening for Down syndrome (DS) is a routine part of prenatal care in many countries, and there is growing interest in the choices women make following a prenatal diagnosis of DS. This review describes what is known about actual and hypothetical decision making following a prenatal diagnosis of DS and adds understanding about the factors that influence women's decision making.

Methods: A search of empirical studies was conducted through electronic databases, major journals, and reference lists that were published in English between January 1999 and September 2010. Inclusion criteria were that the research explored attitudes toward continuation of pregnancy or induced abortion for DS and included at least 1 variable that explored factors influencing women's decision making following a prenatal diagnosis of DS. Studies that did not specify DS, unpublished manuscripts, review articles, and book chapters were excluded.

Results: A total of 11 studies were identified that met the inclusion criteria. The decision to undergo an induced abortion varied depending on whether participants were prospective parents recruited from the general population (23%-33% would terminate), pregnant women at increased risk for having a child with DS (46%-86% would terminate), or women who received a positive diagnosis of DS during the prenatal period (89%-97% terminated). Multiple factors influence women's decision making following a diagnosis of DS, including demographic factors such as religion, maternal age, gestational age, number of existing children, and history of induced abortion. Psychosocial factors including perceived parenting burden/reward, quality of life for a child with DS, attitudes toward and comfort with individuals with disabilities, and support from others also are important influences.

Discussion: Multiple factors influence the decisions pregnant women make following the diagnosis of fetal DS. Therefore, it is critical that health care providers who work with pregnant women are aware of these factors.

J Midwifery Womens Health 2012;57:156-164 © 2012 by the American College of Nurse-Midwives.

Keywords: decision making, Down syndrome, induced abortion, prenatal diagnosis

INTRODUCTION

Down syndrome (DS) is the most common chromosomal disorder associated with various levels of physical and intellectual disability.¹ Down syndrome occurs in people of all races and ethnicities, and it is not concentrated in any socioeconomic group. The incidence of DS increases with maternal age. For example, the chance of giving birth to a child with DS is 1 in 1480 for a woman aged 20 years who gives birth at term and is 1 in 267 for a woman aged 36 years who gives birth at term.² Due to this increased risk, women who become pregnant and who are aged 35 years or older have been screened for DS routinely. However, the majority of children with DS are born to women who are aged less than 35 years when they give birth. Thus, the American College of Obstetricians and Gynecologists advises that "all pregnant women should be offered screening" before 20 weeks' gestation regardless of their age.² As a result, most pregnant women must decide whether or not they will undergo prenatal screening. Given the screening test results, they may face further decisions about undergoing diagnostic testing (eg, amniocentesis, chorionic villi sampling) and whether to continue their pregnancies to term, if the diagnostic test reveals a fetus that has DS.

Advances in molecular genetics and genomics have enabled genetic screening and diagnostic tests during pregnancy

that have high rates of detection of chromosomal abnormalities.³ However, the increased availability of screening and testing options also has resulted in growing concerns about the ethical and social implications of routine prenatal screening and subsequent diagnostic testing.⁴ During the past 2 decades, a great deal of attention has been given to women's reproductive autonomy in relation to their informed decision making. Numerous studies have been conducted to examine factors that influence pregnant women's decision-making processes⁵⁻¹⁰ and their knowledge^{7,11-13} and/or attitudes toward prenatal screening^{9,10,12-14} and testing.^{12,14} On the other hand, little is known about women's decision making following a prenatal diagnosis of DS and the factors that influence these decisions.

Rates of induced abortion (often referred to as termination rates in earlier articles) vary across types of conditions and cultures. According to the review of 20 published studies by Mansfield et al,¹⁵ DS has the highest average rate of induced abortion (92%) when compared to other conditions such as spina bifida, anencephaly, Turner syndrome, and Klinefelter syndrome in European countries and in the United States.¹⁵ Women's responses to induced abortions also vary. Some women who underwent induced abortions due to fetal abnormalities had an increased risk for short-term¹⁶⁻¹⁹ (up to 1 year) and long-term²⁰⁻²² (2-7 years) psychological morbidity such as posttraumatic symptoms and/or depression. In particular, women who experienced more difficulty, ambivalence, or doubt with their decision to terminate their

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pregnancies were more likely to report negative psychological outcomes.^{18,19}

Despite high rates of induced abortion (eg, 60% average, confidence interval, 58%-62% in European countries)²³ as well as reports of both short-term and long-term psychological consequences of the decision to undergo an induced abortion following the diagnosis of a fetal abnormality,¹⁶⁻²² little attention has been paid to the factors that play a role in women's decision making following a prenatal diagnosis of DS. Thus, the purpose of this integrative review is to describe what is known about actual and hypothetical decision making following a prenatal diagnosis of DS and to explore factors that influence decision making from the perspectives of pregnant women in particular and prospective parents in general. The term "termination of pregnancy" is no longer considered the best term for induced abortion in the first half of pregnancy. However, it is the term used in many of the articles reviewed. Therefore, termination of pregnancy will be used when findings from specific studies are reported. Otherwise, the term induced abortion is used.

METHODS

The integrative review method proposed by Whittemore and Knaf²⁴ was used as the guiding framework for this integrative review. This method includes 5 stages: problem identification, literature search, data evaluation, data analysis, and presentation of results.

After identifying the problem to be addressed in this review, which was lack of knowledge regarding decision making following a prenatal diagnosis of DS, as well as the variables of interest, which were rates of induced abortion following the prenatal diagnosis of DS and factors influencing actual and hypothetical decision making concerning the continuation or termination of pregnancy affected by DS, several search strategies were used to identify studies published in English between January 1999 and September 2010. We chose this time period because Mansfield et al¹⁵ had already conducted a systematic review of literature from 1980 to 1998 on women's actual decision making in relation to termination rates for 5 conditions. Our goal was to update their findings as well as describe factors in the current published research that influence decision making in pregnant women following a prenatal diagnosis of DS.

Relevant articles were identified through electronic databases PubMed, CINAHL, and Google Scholar, hand searches of major journals included *Prenatal Diagnosis*, *Journal of Applied Social Psychology*, *Journal of Special Education*, *Psychology & Health*, and the *American Journal of Obstetrics & Gynecology*, and reference lists were taken from identified articles. The following keywords were used in combination: Down syndrome, attitude, abortion, termination, (positive) prenatal diagnosis, diagnostic test, and decision making. Inclusion criteria for this review were 1) findings from the perspectives of pregnant women in particular and prospective parents of reproductive age in general; 2) research focused on the description of decision making or factors that may influence decision making for the continuation of pregnancy or induced abortion following a prenatal diagnosis of DS; 3) if qualitative, research that explored attitudes

toward continuation of pregnancy or induced abortion for DS; and 4) if quantitative, research that included at least 1 variable that explored factors possibly associated with decision making concerning continuation of pregnancy or induced abortion following a prenatal diagnosis of DS. Exclusion criteria for this review were 1) studies that included positive diagnostic test results for fetal abnormalities but did not specify DS and 2) unpublished manuscripts (eg, abstracts, dissertations), review articles, and book chapters.

With respect to the quality of the studies included in this review, we included studies published in peer-reviewed journals only. Thus, all of the studies we reviewed have met some type of quality standard. None of the studies reviewed were excluded due to quality issues if they had already met the inclusion criteria; instead, their methodological weaknesses are described in the discussion section. Five processes were used in analyzing the data obtained for this review: data reduction, data display, data comparison, conclusion drawing, and verification. First, data elements such as study participants, country, type of study, sample size, rate of induced abortion due to DS, and influencing factors of decision making were extracted. Then, these elements were displayed in a data matrix (Table 1).²⁵⁻³⁵ Next, the data elements were compared, and conclusions were drawn. Finally, the conclusions were verified by reviewing the primary sources again.

FINDINGS

Characteristics of Studies Included in the Review

A total of 40 studies were identified through electronic databases, manual searches, and a review of abstracts and reference lists of identified articles. Three articles that did not specifically focus on decision making were excluded. Twenty-five of the remaining studies were excluded because they focused on decision making about whether to have prenatal screening. One article that included positive diagnostic test results for fetal abnormalities but did not specify DS was excluded from the remaining 12 studies. Thus, the remaining 11 studies were included in this integrative review (Figure 1).

All 11 studies that met the inclusion criteria were descriptive, cross-sectional studies. Nine were quantitative^{25,27,28,30-35}; the remaining 2 used a mixed methods approach.^{26,29} Four studies asked prospective parents what they would do in hypothetical situations if they or their partners had a fetus with abnormalities (including DS).²⁵⁻²⁸ In particular, 1 study was conducted with women who had a sibling with DS.²⁶ Three studies examined pregnant women who were offered prenatal screening for DS²⁹ or who were at increased risk of carrying a fetus with abnormalities (including DS).^{30,31} The 4 remaining studies examined women's actual decisions following a prenatal diagnosis of DS. Two were based on chart reviews,^{32,35} and 2 were based on a survey of women who had abnormal findings during pregnancy and who made a decision to continue or terminate the pregnancy³⁴ or who terminated a pregnancy due to DS.³³

The selected studies were conducted in 7 countries: 3 in the United States, 2 in the United Kingdom, 2 in Canada, 1 in the Netherlands, 1 in Uruguay, 1 in Israel, and 1 in Hong Kong, China. The sample size ranged from 69 to 1467. Only 1 study used a guiding framework (intergroup contact

Table 1. Decision Making Following a Prenatal Diagnosis of Down Syndrome in Actual and Hypothetical Situations						
Study Participants	Reference ²⁵⁻³⁵	Country	Type of Study	Sample	Rate of AB due to DS	Factors of Decision Making
Prospective parents, hypothetical situation	Bell, 2000 ²⁵	US	Descriptive quantitative	166 undergraduates, no direct pregnancy experience	Of the 124 who answered: 23% AB 34% unsure 43% no AB	Attitudes toward individuals with disabilities (including DS); degree of personal comfort around individuals with disabilities; church attendance; perceived quality of the child's life; general attitude toward induced abortion
				78 women, sibling with DS	33% AB 14% unsure 53% no AB	Religion; maternal age; general attitude toward induced abortion; perceived burden of caring for a child with DS; sibling characteristics (age, mental health problems); sibling relationship; perceived family approval of induced abortion for DS
				355 employees	N/A	Religion; attitudes toward disability; expectation for parenting rewards; perceived social support
Pregnant women, hypothetical situation	Lawson, 2006 ²⁷	Canada	Descriptive quantitative	280 childless young adults	N/A	Quality of personal relationship; degree of personal comfort in past interactions with individuals with DS; expectation for parenting rewards
				197 pregnant women, offered 2nd trimester prenatal screening for DS	46% AB 28% unsure 26% no AB	Attitudes toward individuals with DS
	Lawson, 2010 ²⁸	Canada	Descriptive quantitative			
	Bryant, 2009 ²⁹	UK	Descriptive mixed methods			

Continued

Table 1. Decision Making Following a Prenatal Diagnosis of Down Syndrome in Actual and Hypothetical Situations						
Study Participants	Reference²³⁻³⁵	Country	Type of Study	Sample	Rate of AB due to DS	Factors of Decision Making
	Leung, 2004 ³⁰	Hong Kong China	Descriptive quantitative	122 pregnant women, attending counseling clinic	86.1% AB 9% no AB, but option should be available 1.6% no AB and option should not be available	Religious background; history of induced abortion
Women who made a decision following a diagnosis of DS	Roberts, 2002 ³¹	US	Descriptive quantitative	69 pregnant women at risk for carrying fetus with a disability, eg, DS or SB	60.9% AB for DS 65.2% Ab for SB	Knowledge of available disability related services; perceived burden of caring
	Britt, 2000 ³²	US	Descriptive quantitative	142 pregnancies of DS ^a	90% terminated 10% continued	Existing children; gestational age; history of AB; maternal age
	Korenromp, 2007 ³³	Netherlands	Descriptive quantitative	71 women, TOP for DS ^b	49% had some doubt about decisions	Concerns for the well-being of siblings; concerns for child with DS; burden for herself and family; perceived influence of partner and health care providers
	Quadrelli, 2007 ³⁴	Uruguay	Descriptive quantitative	207 women (87 with DS) diagnosed with chromosomal abnormality ^c	89% terminated 11% continued	Maternal age
	Zlotogora, 2002 ³⁵	Israel	Descriptive quantitative	1467 pregnancies diagnosed with abnormality (584 with DS; 510 Jews, 74 Arabs) ^a	Among Jewish women: 96.8% terminated 3.1% continued Among Arab women: 89.2% terminated 10.8% continued	N/A

Abbreviations: AB, induced abortion; DS, Down syndrome; N/A, not applicable; SB, spina bifida; TOP, termination of pregnancy.

^a Chart review.

^b Survey by questionnaires.

^c Survey by telephone.

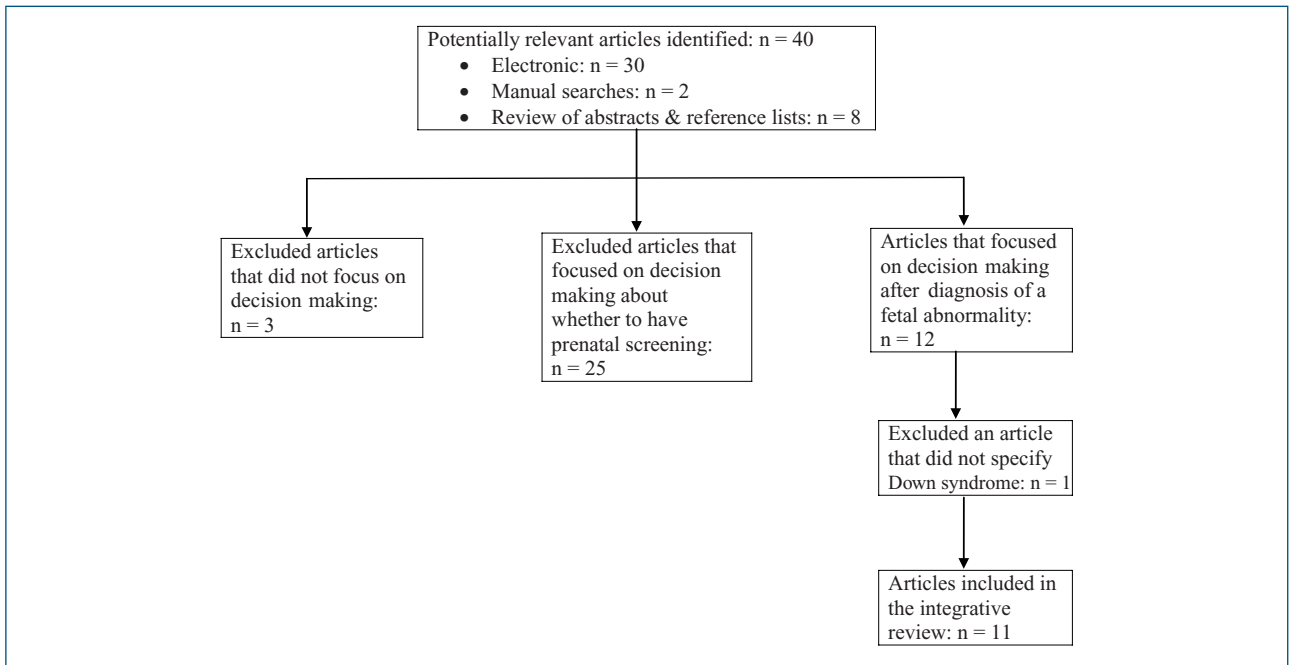


Figure 1. Flow Chart of Study Identification

theory).²⁸ Eight studies reported induced abortion rates for either an actual or hypothetical diagnosis of DS. Ten studies reported factors that influenced women's decision-making processes.

Rates of Induced Abortions for Down Syndrome

Rates of induced abortion due to DS varied depending on whether study participants were prospective parents recruited from the general population, pregnant women at increased risk for having a child with DS, or women who received a positive diagnosis of DS during the prenatal period. Among the first group, 43% of a sample of undergraduates who had never been pregnant indicated they would be willing to continue the pregnancy to term following a diagnosis of DS, while only 23% indicated they would terminate the pregnancy due to DS, and 34% were unsure.²⁵ Thirty-three percent of a sample of women who had a sibling with DS reported that they would consider termination of pregnancy, while 53% indicated that they would not consider termination of pregnancy at all, and 14% were unsure.²⁶ Of 197 pregnant women who were offered second trimester screening for DS, 46% reported they would terminate their pregnancies,²⁹ whereas 86% of pregnant women attending a counseling clinic in Hong Kong, China (n = 122)³⁰ and 60.9% of pregnant women from the United States who were at increased risk for carrying a fetus with DS or spina bifida reported that they would consider termination of pregnancy (n = 69).³¹

In a study of pregnant women from the United States (N = 142) who tested positive for DS, 90% made a decision to terminate the pregnancy,³² while in a similar study of pregnant women in Uruguay, 89% decided on termination of pregnancy (n = 207).³⁴ In the study conducted by Zlotogora³⁵ in Israel, 96.8% of the Jewish women (n = 510) terminated their pregnancies due to DS, whereas 89.2% of the Arab women

(n = 74) chose to terminate. The rate of termination was also different based on the type of diagnostic test. For example, in both groups of women (Jewish and Arab), all women who tested positive for DS through chorionic villus sampling chose to terminate. However, following a positive diagnosis of DS via amniocentesis, 96.6% of Jewish women and 88.7% of Arab women chose to terminate.³⁵

Findings from a survey study by Korenromp et al³³ conducted with 71 women who had undergone termination of pregnancy for DS revealed that 44% had some level of doubt about their decision, 21% had a high level of doubt, and 35% had no doubt at all. Reasons that these women most frequently indicated for doubt included, "My reason was in conflict with my feelings" (49%); "I had the feeling of killing a child" (43%); and "My partner and I disagreed" (38%).³³

Factors that Influence Decision Making

Findings from the studies reviewed suggest that multiple factors may influence actual and hypothetical decision making following a diagnosis of DS. These factors fell into 2 categories: demographic factors—religion, maternal age, gestational age, existing children, and history of induced abortion; and psychosocial factors—perceived parenting burden/reward, quality of life for a child with DS, attitudes toward and comfort with individuals with disabilities, and support from others.

Demographic Factors that Influence Decision Making

Religion

Findings from 4 studies suggest that religion can play a significant role in the decision to continue a pregnancy affected by DS or to undergo an induced abortion.^{25–27,30} Bryant et al²⁶ found that religion is a significant influence on participants' attitudes toward termination. In the study Lawson²⁷

conducted with men and women responding to hypothetical decision making, the strength of religious beliefs accounted for approximately 13% of variance in the willingness to terminate a pregnancy due to DS, meaning that the more religious the participants were, the less willing they were to terminate the pregnancy. Pregnant women from Hong Kong, China, who had a religious background were less likely to accept termination of pregnancy due to DS than those who did not.³⁰ Bell and Stoneman²⁵ found that decreased church attendance was associated with increased willingness to terminate a pregnancy. That is, participants who attended church less often than once a week were more willing to consider undergoing an induced abortion.

Maternal Age

Decisions differed by the age of the women in 2 studies; however, the findings were mixed.^{26,34} Bryant et al²⁶ found that the age of women who were willing to consider termination of pregnancy was, on average, 6.8 years older than those who would not consider termination of pregnancy due to DS. In contrast, Quadrelli et al³⁴ found that the age of women who did terminate a pregnancy due to DS was, on average, 4.3 years younger than that of those who continued their pregnancies.

Existing Children, Gestational Age, and History of Induced Abortion

Other factors that may play a role in decision making about induced abortion for DS include existing children, maternal age younger than or equal to 37 years or older than 37 years, prior voluntary abortions, gestational age less than or equal to 16 weeks or greater than 16 weeks, and history of an induced abortion. In a retrospective chart review by Britt et al³² of pregnant women who had a fetus with DS, women who were at 16 weeks' gestation and under and already had children were 26 times more likely to terminate a pregnancy for DS than those who were at 17 weeks' gestation and over and who did not already have children. This was true regardless of maternal age and previous abortion experience. However, women who were aged 37 years or older who became aware of the diagnosis of DS before 16 weeks' gestation and who had not terminated a previous pregnancy were more likely to terminate a pregnancy for DS (odds ratio 38:1).³²

In a study of pregnant women in Hong Kong, China, women who had no prior induced abortion were less likely to consider an induced abortion following a diagnosis of DS after 24 weeks' gestation.³⁰

Psychosocial Factors that Influence Decision Making

Perceived Parenting Burden/Reward

Five studies reported on the perceived burden of caring for a child with DS.^{26–28,31,33} Among 78 women who had a sibling with DS, 56% of the 42 women who indicated they would probably or definitely undergo diagnostic testing indicated that they would do so because they would terminate a DS pregnancy.²⁶ They went on to indicate that their reason for terminating a DS pregnancy was that having a sibling with DS had a negative impact on themselves and their families. On the other hand, 27% of the women who indicated they would

probably or definitely undergo diagnostic testing said they would not consider terminating a DS pregnancy but wanted to be prepared for the birth of a baby with DS if the test results were positive. The remaining 17% indicated that they wanted diagnostic testing because in the event of positive results, they would make their decisions to continue or terminate the pregnancy based on their current circumstances and their partners' wishes.²⁶

In the study by Roberts et al,³¹ 95.7% of participating women expected an increased burden in their roles as primary caregivers, and 60.9% who said they would choose termination of pregnancy attributed that decision to the anticipated increased parenting burden. In the same vein, Korenromp et al³³ reported that more than half of 71 women who received a positive diagnosis of DS during the prenatal period and chose termination of pregnancy indicated the following reasons for that decision: the burden for themselves (64%), the burden for other siblings (73%), their relationship (55%), disfavor of having a disabled child (63%), and unhappiness with having this newborn (61%).

In contrast to perceptions of burdens, 2 studies done by Lawson^{27,28} highlighted perceptions of parenting reward from caring for a child with DS as a significant factor by which prospective parents may be influenced. Participants who perceived more personal reward and personal enrichment from parenting a child with DS were less likely to choose to undergo an induced abortion due to DS. In addition, those who were more familiar with individuals with DS perceived more parenting reward and were less favorable to choosing an induced abortion due to DS. The relationship between quality of prior contacts with individuals with DS and willingness to terminate a DS pregnancy was partially mediated by perceptions of parenting rewards from caring for a child with DS.²⁸

Quality of Life for a Child with Down Syndrome

Two studies measured perceived quality of life for a child with DS.^{25,33} Forty-three percent of the participants who made a hypothetical decision to continue a DS pregnancy reported the perception of a good quality of the child's life with DS, whereas 23% of respondents indicated the choice of termination of pregnancy on the basis of the perception of a poor quality of life for a child with DS.²⁵ Moreover, 71 women who terminated their pregnancies due to DS reported that they made that choice because, "I believed the child would never be able to function independently (92%)," "I considered the abnormality too severe (90%)," "I considered the burden for the child itself too heavy (83%)," "I worried about the care of the child after my/our death (82%)," "I considered the uncertainty about the consequences of the abnormality too high (78%)," and "I thought that respect for disabled children in our society is too low (45%)."³³ Interestingly, those who were not sure about their decisions (34%) also indicated the quality of the child's life as a main reason for ambivalence.²⁵

Attitudes Toward Individuals with Disabilities

Three studies reported on how the influence of attitudes toward individuals with DS affected the decision-making process of induced abortion due to DS.^{25,27,29} Participants had more negative attitudes toward individuals with DS than

toward individuals with muscular dystrophy or individuals without disabilities.²⁷ Participants with negative attitudes toward individuals with disabilities (including DS) were more likely to choose induced abortion than those who had more positive attitudes.^{25,27} The same result was demonstrated by pregnant women with regard to their intention to choose induced abortion.²⁹

Personal Comfort with Individuals with Disabilities

Three studies highlighted findings about the relationship between personal comfort with individuals with disabilities (including DS) and attitudes toward induced abortion and decision making.^{25,26,28} Respondents who felt more comfortable with individuals with disabilities had more intention of continuing the pregnancy than those who felt less comfortable.²⁵ The quality of previous contact with individuals with DS and the degree of personal comfort in those interactions also were associated with the intention of choosing induced abortion, in that participants who had good relationships with individuals with DS were less likely to consider induced abortion than those who had poor relationships.²⁸ In addition, women who had a sibling with DS in their families and had a good relationship with their siblings reported less willingness to choose induced abortion due to DS.²⁶

Support from Others

Two studies examined the relationship between the influence of others and decision making following a prenatal diagnosis of DS.^{26,33} The study of Bryant et al,²⁶ conducted with women who had a sibling with DS, revealed that perceived family approval of termination of pregnancy due to DS, along with the perceived burden of care and general attitude toward termination were the strongest predictors of willingness to terminate a pregnancy due to DS. In the study by Korenromp et al³³ of women who received a prenatal diagnosis of DS and chose induced abortion, 74% reported that contact with their partner greatly influenced their decision making, and of those who had contact with family and friends, 37% reported a substantial amount of influence from these contacts. Of the women who had contact with a religious provider, 45% perceived this contact as influential.³³ The percentages of contact made with a partner, family/friends, and a religious provider were 97%, 84%, and 16%, respectively. The influence of contacts with health care providers including geneticists, obstetricians, family doctors, and midwives on the decision-making process was substantial (18%-42%) as well, although the majority of women indicated that they did not feel pressure from these health care providers. However, 13% of 71 participating women reported that they perceived pressure during their decision-making process from societal values, religious values, family or friends, and medical staff.³³

Two studies reported an association between perceived social support and the decision-making process.^{27,31} The more participants perceived social support for parenting a child with a disability, the less likely they were to choose induced abortion.²⁷ Moreover, knowledge of available services for people with disabilities rather than knowledge of disabilities was an important factor in the decision to continue a pregnancy affected by a disability.³¹ Thus, women with higher

knowledge of available services were more likely to continue their pregnancies.

DISCUSSION

Findings from this integrative review of studies conducted between January 1999 and September 2010 suggest that induced abortion rates for pregnancies affected by DS are similar to those reported in a review of similar studies conducted from 1980 to 1998.¹⁵ However, in the studies reviewed for this article, induced abortion rates for actual pregnancies in which there was a diagnosis of DS were significantly higher than induced abortion rates for hypothetical situations. One explanation for this is that participants who have not actually received a prenatal diagnosis of DS may underestimate their willingness to consider undergoing an induced abortion because of the diagnosis of DS. Another explanation is that participants may be responding in a manner they think will be reviewed favorably by others.

Hypothetical decision making about induced abortion due to DS also seems to vary in different cultures. For example, the responses from pregnant women at increased risk of having a child with DS in Hong Kong, China, were different from those in the United States. These 2 countries are different in terms of attitudes about individualism and collectivism.³⁶ Cultures that stress individual contributions to society within a collectivistic standpoint are more likely to have more influence on women's decisions³⁶ and to provide fewer resources as well as negative information for the family and individuals with disabilities.³⁷ Moreover, women who choose to continue their pregnancies with DS in these societies may be considered to be responsible for all care concerning their child with DS because they elected to have the child.³⁸

Unlike the review by Mansfield et al,¹⁵ which determined rates of induced abortion following a diagnosis of fetal abnormality, this review identified multiple factors that influence women's decision making following a prenatal diagnosis of DS. These include both demographic factors and psychosocial factors. Of these 2 types of factors, the ones that are the most amenable to intervention are the psychosocial factors. Therefore, health care providers should focus on making sure women have the information they need to make well-informed decisions. For example, if a woman makes a decision to undergo an induced abortion following a prenatal diagnosis of DS based on inaccurate or outdated information about life with a child who has DS, she may ultimately regret her decision once she learns about current care practices for individuals with DS that allow many individuals with DS to lead long, productive lives.³⁹⁻⁴¹

Clinical Implications

Health care providers who counsel women following a prenatal diagnosis of DS need to provide accurate, up-to-date information about the care practices for individuals with DS, quality of life for individuals with DS, and types of resources available for individuals with DS and their families. Moreover, health care providers need to be aware of their own attitudes toward and comfort with individuals with disabilities, because these factors are likely to have an influence on a provider's ability to give balanced, up-to-date information. To provide

better insight into the life of a child with DS and life with a child with DS, health care providers can give pregnant women the option of talking with parents of children with DS following the prenatal diagnosis of DS. Counseling also needs to include partners and other family members in prenatal and postnatal counseling, if that is the woman's preference. Furthermore, individualized follow-up care plans should be established for women and their partners once a decision has been made (continuation of pregnancy or induced abortion). In a study by Elder and Laurence,⁴² women who received follow-up care after terminating a pregnancy due to a fetal abnormality experienced significantly fewer adverse emotional consequences than women who did not receive follow-up care.

Unfortunately, many of the health care providers who counsel pregnant women and their families following the diagnosis of DS lack the expertise needed to provide appropriate counseling. Therefore, there is a critical need for health care providers to recognize the type of expertise necessary to counsel pregnant women and their families following the diagnosis of DS and other conditions. Those who lack the necessary expertise should either seek out additional training or be prepared to refer their patients to providers who do have the necessary expertise. In addition, they need to be aware of resources that may be helpful such as the Brighter Tomorrows Web site (<http://www.brightertomorrow.org/>). This Web site provides accurate, up-to-date information for pregnant women who have just received a prenatal diagnosis of DS as well as those who have just been told their child has DS.

In 2008, the Prenatally and Postnatally Diagnosed Conditions Awareness Act⁴³ was signed into law. This act requires that families who receive a diagnosis of DS or another condition, prenatally or up until a year after birth, be given accurate, up-to-date information and support. In addition, it authorizes the secretary of the Department of Health and Human Services to 1) collect and disseminate evidence-based information on Down syndrome and other conditions diagnosed either through prenatal genetic testing or screening or in the 12-month period beginning at birth; 2) establish a resource telephone hotline for new or expectant parents; 3) expand and further develop local and national networks for peer support, outreach, and information to parents; 4) establish awareness and education programs for health care providers who talk to parents about prenatal genetic testing; and 5) set up a national registry or network of local registries of families interested in adopting newborns with Down syndrome and other conditions. It is hoped that efforts such as these will help in ongoing efforts to provide better information and support to women and families following the diagnosis of DS and other conditions.

Because the findings of this review are based on a relatively small number of studies, it is important to mention the limitations of these studies. Sample size varied from 78 to 1467. Only 1 study justified the sample size.³¹ In some of the studies reviewed, the measures used did not have strong psychometric properties. Only 2 studies used a guiding framework²⁸ or an analytic technique for chart review.³² In addition, the rate of induced abortion due to DS in hypothetical situations may be different from that of an actual decision in relation to carrying a fetus affected by disabilities (including

DS). Thus, caution must be used when comparing these rates. Moreover, the decision making of women living in countries where induced abortion is legal may be different from the decision making of those in countries where induced abortion is illegal. Therefore, different cultural backgrounds also should be taken into account, and thus these findings may not be generalizable to all populations.

CONCLUSION

Multiple factors influence the decisions pregnant women make following the diagnosis of DS. Health care providers need to be aware of these factors, especially the psychosocial factors, because psychosocial factors are the ones most strongly influenced by the nature and type of information providers give to pregnant women and their families following the prenatal diagnosis of DS. It is imperative that the information is provided in a nonbiased manner and that it is accurate. More importantly, it needs to include the full range of options as well as resources.

There is currently an urgent need for more research concerning the type of information and support pregnant women and their families receive following the diagnosis of DS. Research that uses a qualitative approach with a diverse sample would greatly enhance our understanding of women's decision making regarding induced abortion due to a diagnosis of DS. Currently, much of what has been written about the type of information and support provided following a prenatal diagnosis of DS has been based on reports by health care providers or women who chose to continue their pregnancies following a diagnosis of DS. The voices of women who chose to terminate their pregnancies is conspicuously absent from the literature. Moreover, there have been few longitudinal studies examining the long-term psychological consequences of the decisions women make surrounding the diagnosis of DS. Intervention studies for women who undergo a tough decision-making process following a diagnosis of DS also need to be conducted.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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